Effective interventions: 25 years outside the mainstream

3140 words excluding references

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Abstract

25 years ago when the Durham conferences were in full swing, I presented results of investigations on language and behaviour in autism. I tentatively proposed that early language in autism might tell us about the cognitive skills of people with ASD and the behaviour might lead to greater understanding of which brain systems might be affected. In this presentation, I will update these topics and present a summary of other work I have been involved with in attempting to improve the lives of people with autism and their families.

Data on three people with autism at the early stages of speech development showed an unusual pattern of learning colour and number names early. One possibility was that this skill represented a sign of weak central coherence – they only attended to one dimension. Colleagues of mine were equally puzzled so we tried to find out if my results could be replicated – they were not (see Schafer, Williams & Smith, 2014). Instead we found this pattern was also seen in Down Syndrome, but that early vocabulary in autism was associated with low Colorado Meaningfulness at least in comprehension. The Colorado Meaningfulness of a word is a measure of how many words can be associated with it and often involve extensive use of context. Our data suggest that the number of contexts in which a particular word can appear has a role in determining vocabulary in ASD which is consistent with the weak central coherence theory of autism. In the course of this work I also came across a group of young people with autism who appeared to have a written vocabulary but not a spoken one. It seems possible that print might be a medium of communication when speech is not.

Repetitive behaviour in autism remains a mystery. We can use functional analysis to determine why the behaviour occurs, but a worryingly large percentage of behaviours are described as being internally driven or sensory reinforced. What does that mean in terms of brain activity – could it be system analogous to epilepsy, where brain activity becomes inappropriately synchronised? At the moment I cannot claim to have solved this problem, but if sensation is a driver then sensory interventions should make a difference. Data from a recent study will be presented to suggest that for some individuals this is the case.

Social behaviour remains the key however, and it remains to be seen whether it is possible for social behaviour to be aided. One route that has potential is direct teaching of skills through drama and working with others who do not have social difficulties of the same type. The picture is complicated by changes in social skills with age and experience, but the failure of people with ASD to interact when in settings of social contact is little researched.

Effective interventions: 25 years outside the mainstream

It is 25 years since I attended the first Durham conference. It is fitting therefore that should review my research on the autism spectrum disorders (ASD) over that time. I will first consider my research in the context of the new DSM5 description of ASD, before reviewing some work on issues that are only now being discussed as typical of ASD.

In DSM5, ASD is defined in terms of two clusters of signs and symptoms: social communication difficulties and repetitive and stereotyped behaviours including insistence on sameness. DSM5 also mentions the unusual sensory behaviours of people with ASD, without bringing them in to the diagnostic framework. Finally there are difficulties that are more common in ASD than in other groups e.g. sleep difficulties that also warrant intervention.

Social Communication

Social interactions

At the age of 12, I met my first child with ASD. A family moved in to the house behind us The four eldest of us children played together, because the fifth child (the neighbours' youngest) had autism and largely ignored us. Occasionally he would spend an hour or so with us while his mother took his two elder sisters out shopping which he did not tolerate. We were told to watch him, and that he would not be able to play with us. However, he did tolerate some interaction and could play alongside us in the dirt. I do not remember him speaking, but I do remember violent temper tantrums when he would hit his head against the outer wall of their house. I still work with children like him.

About ten years later I started work at a psychiatric unit for children with ASD. Influenced by Tinbergen (Tinbergen & Tinbergen, 1972) and his collaborator Richer (Richer & Richards, 1975), I researched ways in which social interactions could be modified to improve the learning of children with the most severe forms of autism (Williams, 1987). At the same time I met young people with ASD who were educationally integrated in a local school, but they remained isolated socially. Social skills training for people with mental illness was promising, (Trower et al. 1978; Hollin & Trower, 1988) and was extended to children by Spence (1980). Thus inspired I attempted similar work in ASD (Williams, 1989) although it was rather mechanistic and required more sessions and more effort in generalization than other social skills training programmes. Subsequent research has expanded the range of techniques available for social skills interventions, but the core problem of difficulties in social interaction remains. One promising approach is to intervene throughout the natural environment rather than only the classroom (cf. Williams, 1989). Strain, Kerr & Ragland (1979) had demonstrated that typically developing peers could increase social interactions for children with ASD, so we wondered if siblings siblings could do likewise. Siblings do indeed interact a lot with children with ASD, but like the siblings of children with Down syndrome, they have to lead to a greater extent than their age or experience might predict (Knott, Lewis & Williams, 1995). A 12 month follow up established that there were significant improvements in social interactions between siblings with and without ASD (Knott, Lewis & Williams, 2007). Other authors have found that children with autism become more socially interactive as they grow up (e.g. McGovern & Sigman, 2005) which implies that ASD social behaviour can improve. There remains doubt about whether the improvements can be accelerated. The evidence from programmes to ameliorate long term

disadvantage suggests that only intensive long term interventions are successful (Campbell et al., 2014), whereas the literature on neurological disability in adults suggests that prosthetics (environmental or devices) may be required Kapur, Glisky, & Wilson, (2004). While there is nothing quite like that available for helping the child with ASD to be more socially skilled, there are centres developing robots to teach social skills to children with ASD (Robins, Dautenhahn & Dickerson, 2009).

Communication skills

Williams (1990) reported that a survey of members of the National Autistic Society had shown that one third of young people with ASD were unable to speak. The results also showed that young people with ASD might start speaking at unusually late ages. Even when they start to speak, people with ASD may show unusual patterns of learning. For instance, Williams (1993) found that the early vocabulary of a 3 year old used more colour words than expected. Schafer, Smith & Williams (2013) studied the early vocabulary of three groups of children: ASD, Down Syndrome (DS) and typically developing (TD). We found that children with ASD learnt more words with less semantic links than children with DS matched for vocabulary size, which suggests that children with ASD have a less well developed sense of central coherence. In other words they tend to see the detail rather than the whole ("not seeing the wood for the trees"). However other authors have shown that children with ASD can be instructed to pay attention to the whole rather than the parts could form part of early interventions?

Although many people with ASD do learn to speak, a substantial number do not. They therefore need help communicating. In the 1980s sign language was thought to be promising. The evidence seemed to suggest that it might be easier to learn than speech and even promote

subsequent spoken language (Bonvillian, Nelson & Rhyne, 1981). However, many people with ASD find signing difficult due to poor manual dexterity. Bondy & Frost (1998) devised the Picture Exchange Communication System (PECS) in response. PECS use starts with exchanging pictures with printed words to obtain favoured items and enables development up to simple sentence level. Some people with ASD learn to use the cards without the pictures, (Word Exchange Communication System - WECS). Could WECS users could learn new vocabulary through printed words? This might seem far-fetched, but people with ASD often show exceptional reading skills relative to spoken language (Grigorenko, Klin & Volkmar, 2003). In addition Ricketts, Bishop & Nation (2009) have suggested that new vocabulary can be learnt through reading unknown words. In our study we presented participants with autism who did not speak with a picture of an invented object beneath which was a non-word. We then re-presented the picture in the context of a larger complex drawing of a scene – see figure 1

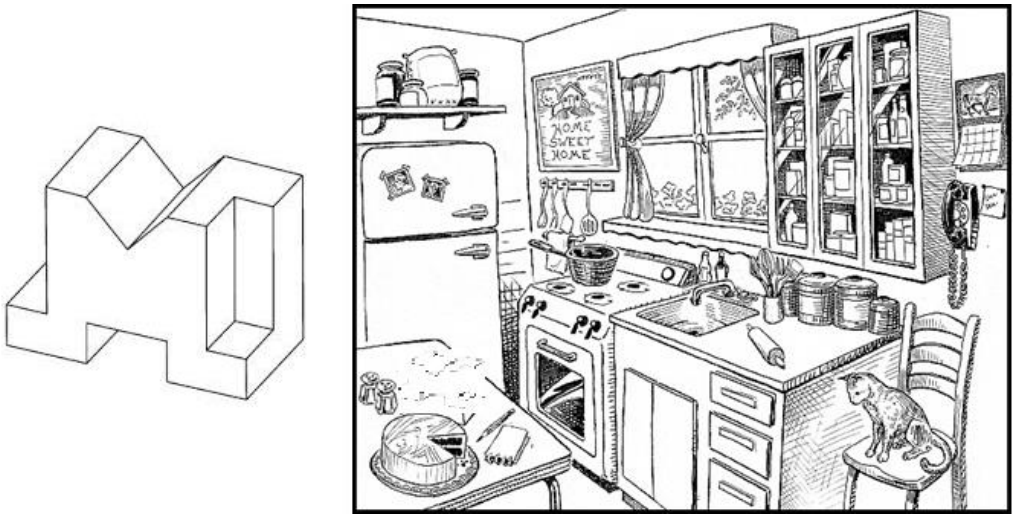

Figure 1 On the left hand side is a “cheem". The child's task was to find the "cheem" in the right hand picture from a written instruction.

We found that young people with ASD and no spoken language were able to learn new names for novel objects at one presentation. This is comparable to the skills of typical young infants

who can learn new object names from very few presentations (Schafer & Plunkett, 1998). If this finding can be extended, some people with ASD might prefer to communicate in writing rather than speech.

Repetitive and stereotyped behaviours

Repetitive, rigid and stereotyped behaviours (RRBs) in ASD are thought to impede learning (e.g. Berkson, 1983) and are problematic for parents and caregivers. Syntheses of published research suggest that all forms of RRBs respond best to treatments informed by a functional analysis (Didden et al. 2007). The gold standard for functional analysis of behaviour is an analogue assessment in which the participant takes part in several controlled environments, considered analogous to real life situations. The most common are:

Alone: individual alone in a room;

Contingent attention: attention (as a verbal request to stop the behaviour) only given after occurrence of a behaviour;

Non-contingent attention: Attention given continuously throughout in the form of verbal "chat";

Demand: Continuous demands to complete an academic task.

Functions are deduced from the strength of the association with each condition. If the method is to be useful it must be both reliable and valid. An initial difficulty comes with defining the function. At least three methods for determining the function exist (Martin, Gaffan & Williams, 1999) which we compared and measured their reliability over a one month period for the RRBs of adult residents of a community home for learning disabilities. The observers were reliable at identifying the behaviours, but the three methods only identified functions for

between 38% and 57% of the identified behaviours. In addition the Cohen's kappa for agreement between methods ranged from 0.42 to 0.54, which is weak. We concluded therefore that the methods for analysing the functions of behavior are not reliable although raters agreed when the behaviours occurred.

Other research at this time suggested that much RRB could be seen as forms of obsessive compulsive disorder (OCD). OCD is defined as the occurrence of distressing thoughts (obsessions) which are relieved by performing rituals (compulsions). To determine if someone has OCD, one should ideally have access to the person's thoughts, which can be problematic in people with ASD. A colleague and I (White & Williams, 2000) interviewed people with Asperger's Syndrome and collectors without ASD. Our results showed that the people with ASD tended to have more idiosyncratic interests than the collectors, and were more upset by not being allowed to indulge in their RRBs. However, they did not report needing the RRBs as a form of reducing distress as occurs in OCD. Instead they reported enjoying RRBs.

Finally, I have long been concerned that I am missing something in the repetitive behaviours of people with ASD. Most of their repetitive behaviours are not driven by fear, distress or anxiety unlike those seen in OCD. In one of the earlier conferences I speculated that using mathematical modelling to understand the distribution of peaks and troughs in repetitive behaviour might illuminate potential brain mechanisms. My attempts so far have not revealed anything helpful. Both in short term time series and in longer time series, it appears that there is no rhythm to the behaviours. In fact it appears that the simplest explanation is that behaviour occurs at random time intervals (see Figure 2). In other words, it may not be predictable on its own.

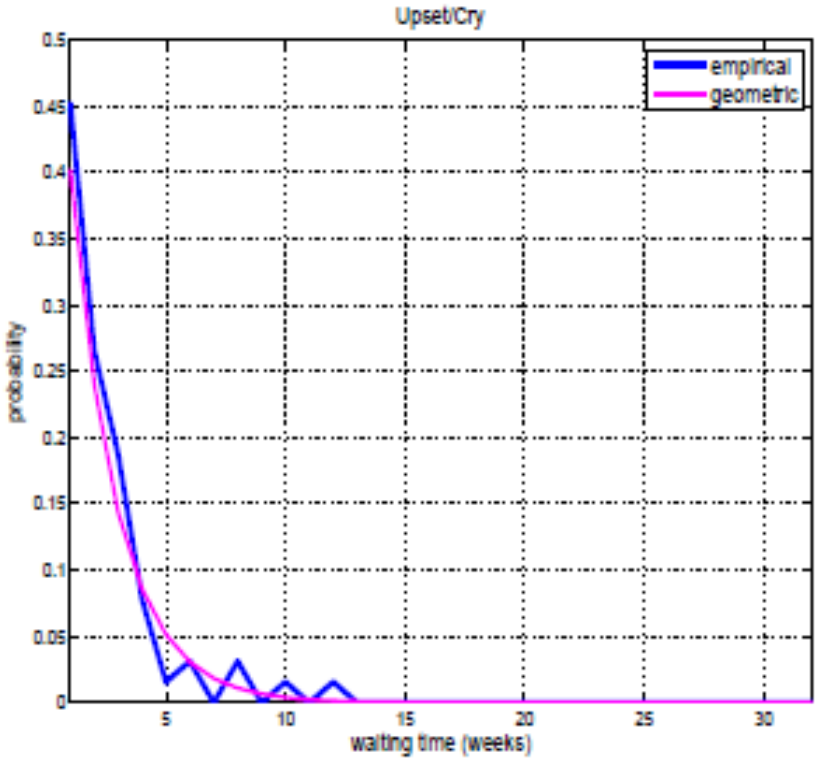

Figure 2 shows the probability of accurrence of a upset/crying behaviours in weeks since the last bout of upset/crying behaviour. The jagged blue line shows the actual distribution and the smooth curve shows a theoretical distribution. The fit of this curve to the observed line is good (MLE estimator = 0.40).

Sensory work

The rationale for my work is to understand the processes behind unusual behaviours and attempt to rectify them. I have therefore been involved in several attempts at evaluating promising interventions.

Multi-Sensory Therapy

Martin, Gaffan & Williams (1998) compared the effects of a multisensory room (MSE) with a condition in which the participants interacted with caregivers. 27 adults with severe ID took part in the study, and the effects were measured in terms of challenging behaviour and on task

behaviour. We also hypothesised that the non-contingent nature of MSE might be particularly beneficial for sensory maintained challenging behaviour. The results showed no significant effect of the MSE nor did sensory maintained behaviours show greater reductions following MSE was also not true. The evidence therefore suggests that MSE is not an effective treatment for RRBs in people with ID. MSE may have other benefits such as enjoyment or promoting interaction, but we did not investigate these.

Massage therapy for sleep

Aromatherapy massage can be viewed as sensory stimulation delivered by pressure to the skin and olfactory stimulation. Studies have found beneficial effects of aromatherapy massage for agitation, for pain relief and for poor sleep in people with dementia. A residential school for children with autism and ID were interested in discovering whether aromatherapy massage could improve the sleep patterns of people with autism. We measured sleep onset, sleep disruptions and sleep duration. The sleep of eleven children with autism and learning difficulties (2 girls and 9 boys aged between 12:2 to 15:7) in a residential school was monitored over a period of three weeks during which they received 3 sessions of aromatherapy massage with lavender oil and 14 nights without. Analysis of the sleep data revealed no changes between nights with aromatherapy massage compared with nights without (Williams, 2007). It seems unlikely therefore that aromatherapy massage has beneficial effects on the sleep of children with autism and severe learning difficulties.

Deep pressure therapy

Deep pressure is widely used by occupational therapists for people with autism spectrum disorders. It is related to Ayres' Sensory Integration Therapy and the "hug" machine of Temple

Grandin. Little is known about its effects on people with ASD, although many benefits are claimed. We recently compared ratings of behaviour and mood before and after deep pressure. *R*atings were made by staff working with 13 pupils with ASD and severe ID. Sufficient data was only available from 8 participants to be analysed using tau-u, a non-parametric technique that allows for serial dependence in data (Parker, Vannest, Davis & Sauber, 2011). Six participants showed benefits statistically of whom 5 showed benefits on all the scales, and one showed benefits on three out of five domains. This suggests that deep pressure may have benefits which should be further investigated.

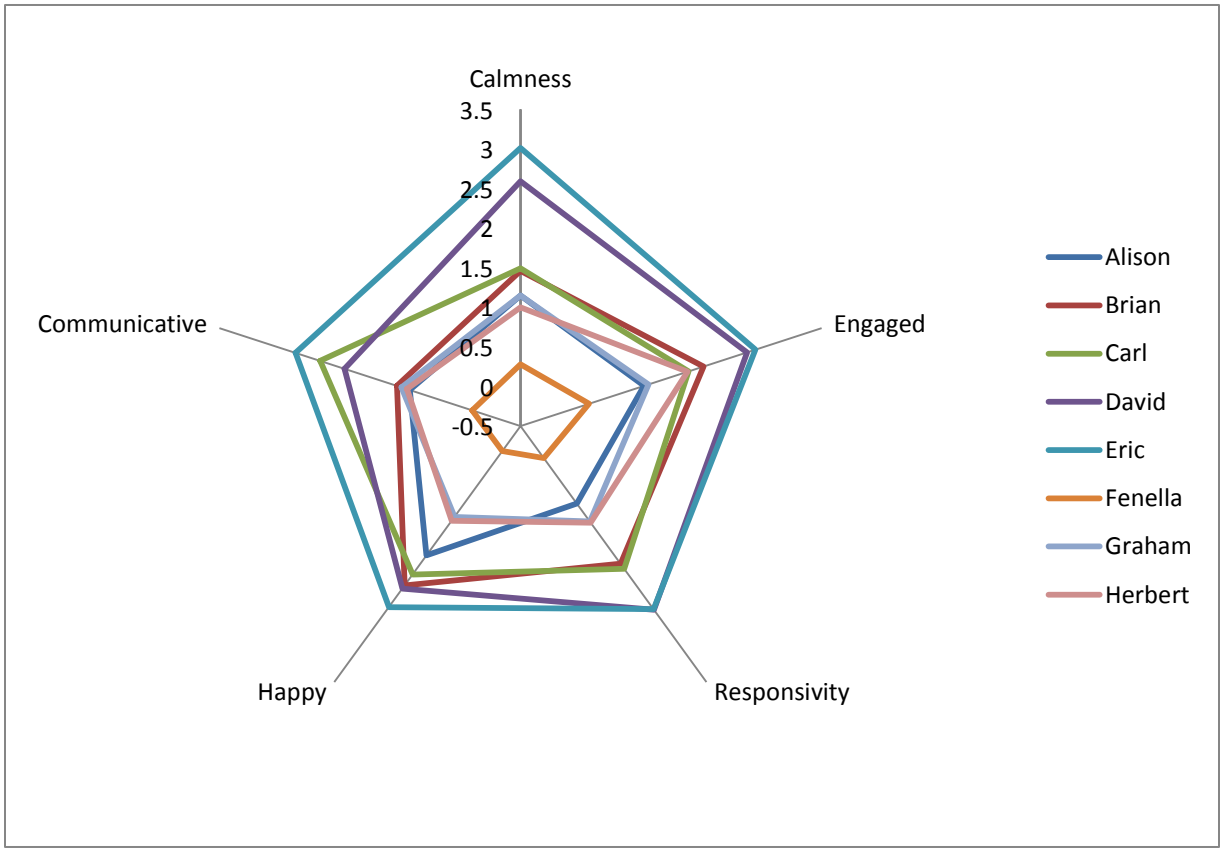

Figure 3 Radar chart showing mean changes in rating scale score before and after deep pressure sessions. The further the score is from the centre the greater the benefit. Most of the change scores were statistically significant, except for those for Fenella whose scores are the most central.

Theory

In my working life theories of autism have changed from those to do with social motivation (Tinbergen, Richer) to cognitive theories (Theory of Mind – Baron-Cohen; Central Coherence – Frith and Happé) while research funds has flowed in to the genetics and the brain structures involved in autism. Each research endeavour has started off with huge optimism, but in a few years the theory is either discredited (e.g. social motivation) or found to be more complex than had been considered likely (genetics – an early estimate of 5-7 gene loci now thought to be around 100).

One promising theory is weak central coherence (WCC), which proposes that people with autism have problems with using details to see the whole, in other words they tend to see the trees but not the wood. An alternative theory is that people with ASD have difficulty changing their plans. So in looking at a wood, you might start by examining a tree. I have been involved in two studies which sought to find out whether there were particular cognitive skills or deficits in autism. The first was a study of musical tone processing whereas the second was concerned with memory skills.

Perfect pitch

Mareike Altgassen asked to research an aspect of autism while she studied in England as part of her degree course in Germany. At about the same time a number of authors had suggested that there was an increased rate of perfect pitch (the ability to detect musical tones accurately) in autism. Our study investigated this by comparing the ability to detect pitch in an embodied context (chords). This is relevant to central coherence theory, because for most people a chord is a unit rather than a collection of individual tones. If, as proposed by Frith &

Happe (1994), people with autism have a tendency to see the parts rather than the wholes (see the trees but not the wood), then they should hear the tones better than typically developing people. Interestingly we only found this pattern for more able children with autism (those then labelled as Asperger's Syndrome).This raises issues about whether people with more severe forms of autism may have multiple deficits, and therefore show problems that might not emerge at more typical levels of ability.

An alternative cognitive theory of autism is that they have a problem of planning, in other words a central executive dysfunction. Planning is often tested by find out how well people can remember to carry out an intended action in the future, which is described a test of prospective memory. Our experiment tested the prospective memory of people with autism and a control group. The results were remarkably different, such that people with autism showed a reduced ability to carry out planned tasks. This result could explain why people with autism find it so difficult to be organized at a school, and may underlie the difficulties that they have with meaningful employment. The question of why this occurs remains difficult to discern. One possibility is that people with ASD are less able to use self-initiated processing such as reduced task monitoring.

Conclusions

In summary, my research over 25 years has investigated both core areas of the autism spectrum (social-communication and repetitive behaviours), and some additional problems (sleep, challenging behaviour, self-organisation) common in ASD on theoretical (weak central coherence) and practical levels (social skills training, assessment of functions of behaviour). The idea that social skills might be taught to people with ASD is significant even if it does mean

using robots for the initial stages. Interventions will need to be long term, in the same way that interventions to overcome any neurologically based problem tend to be. Methods of communication for people with ASD that are less social (e.g. email and text) may prove to be helpful. It might seem a little unusual but gets round the problem of the aversive nature of face to face contact for people with ASD. Repetitive behaviour remains a real puzzle however. I am not yet able to explain robustly what people with ASD are doing when they engage in those repetitive and rigid behaviours except to say that they are designed to make them more comfortable in some way. Is there some way that we can help them develop other less intrusive behaviours which interfere less with their abilities to learn and to interact? People with ASD also have a host of other difficulties to a greater extent than other people. They often have poor sleep patterns, which in part be socially determined. They may be aggressive because they do not understand that there are other ways of solving problems. They may be disorganised because they cannot plan ahead due to an interest in some other aspect of their world that has interfered. Yet they have talents and skills in spinning objects or themselves, in hearing aspects of music that are hard for others to hear and in bypassing conventional understanding. I do not feel that my work has contributed to this area of the life of the person with ASD.

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